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ABSTRACT

The fourth in a series of four booklets on residential programing for mentally retarded persons aims at providing parents with basic information on the operational aspects of institutions so that they can form realistic strategies for implementing change. Negative attitudes of direct care, professional, and administrative staff toward innovative programing are considered. Resistance to change from direct care staff is said to result from adherence to established routines, intershift conflicts, loss of motivation through delays, lack of supervisory effectiveness, and lack of respect from professional aloofness. Illegitimate goals and misplaced concerns of administrative personnel are cited. Problems stemming from the bureaucratic system within which the institution operates are examined. Inservice training programs, redeployment of staff (departmental, unit, and cross modality approaches), and demonstration projects are discussed as means of implementing change. Recommendations for involving parents in decision making processes are included such as representing parents at staff meetings and using parents to obtain institutional access to community based facilities. (For related information, see EC 050 051 through EC 050 053.) (GW)

RESIDENTIAL PROGRAMMING FOR MENTALLY RETARDED PERSONS

The Process of Change

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This series of materials was developed in conjunction with the NARC project **Parent Training in Residential Programming,** supported by grant 56-P-70771-6-01 (R-1) from the Division of Developmental Disabilities, Social and Rehabilitation Service, U. S. Department of Health, Education, and Welfare.

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The Process of Change

NARC believes it is essential that parents become significantly involved in the monitoring and evaluation of residential programs and initiating change. They should determine areas of inadequacy, and ensure needed changes are made. The preceding section **Developmental Programming in the Residential Facility** provided a basis for parents to knowledgeably participate in the evaluation of residential programs. The following section focuses on information which will assist in understanding many of the operational problems which exist within most residential institutions.

Parents are generally not provided with necessary "behind the scenes" information — information essential to the formulation of reasonable, realistic stances. Instead they are expected to "understand" the slow pace of progress, and "accept" the inability to make positive changes. By providing parents with basic information on the operational aspects of institutions, it is hoped that they can more effectively form realistic and reasonable strategies for implementing change.

RECIPIENTS OF RESIDENTIAL PROGRAMS[1]

A basic question regarding any program is "Whom does the program serve?" In the case of residential services for the mentally retarded, the most obvious answer is "Why, the retarded, of course!" Upon closer examination, however, it becomes apparent this conclusion is only partially correct. That is, there are several major groups whose interests are served by residential service programs. Roos (1970) has identified four such interest groups: **society,** the **economist,** the **family** and the **resident.**

The interests of society. Society seems to be particularly concerned with social deviancy. It has little tolerance for persons who look, think or act significantly different from the majority of other citizens. And, since mentally retarded persons frequently fail to conform to cherished cultural norms, society has traditionally demanded that mental retardation programs minimize or eliminate deviancy of the retarded. When residential facilities for the mentally retarded apply such social values, two basic courses of action come to light: 1) residents who have the potential to behave in a non-deviant manner may be directed toward community living; and 2) those who are unable to meet society's tolerance for deviancy are maintained in relative isolation from the community at large.

Tolerance for deviancy obviously differs from culture to culture. Criteria for retention in a residential facility are thus a function of the particular social environment within which the retarded person would have to live and work.

The interests of the economically minded. The economic implications of mental retardation programs are becoming increasingly important in the United States. When considering the allocation of operational funds, key decision makers — such as budget agencies, legislatures and governors' offices — demand maximum efficiency from mental retardation programs. Administrators often attempt to justify program costs on the basis of estimated cost savings to the state. Thus, habilitation programs are frequently funded on the grounds that they will transform "tax burdens into tax payers", while habit training programs for the profoundly retarded may be justified on the basis that they will decrease laundry costs, maintenance expense, or food wastage. Evaluation clinics and alternatives to institutionalization are justified by comparing institutional costs with costs of retaining the mentally retarded at home or at other community facilities.

It cannot be denied that administrators have been successful in "selling" programs on an economic basis. There are inherent dangers, however, in using economic considerations as the principal criterion for services for the mentally retarded. One possible result, for example, is to curtail programs to reduce costs to a minimum.

[1]The materials in this section are based primarily upon several publications by Dr. Philip Roos, Executive Director of NARC. Specific references may be found at the end of this section.

Another strategy, popular in past years, is to obtain maximum work from retarded residents themselves. Institutional farms and industries have only recently been eliminated from many American residential facilities, and "working residents" continue to be critical to the operation of many institutions. Decreasing the need for expensive staff has been used as a justification for some habit training programs, as well as for the development of automated equipment and design of new facilities.

The interests of the family. The families of mentally retarded persons are exerting increasing influence on programs for the mentally retarded. In general, parents are concerned with maximizing the human characteristics of their retarded children. They demand that all possible efforts be expended to humanize their children, to shape them in their own image. Parent groups have, therefore, supported the "principal of normalization" and have attempted to eliminate dehumanizing conditions in residential institutions.

The interests of the retarded. Most programs, however, give only cursory attention to the goals of the retarded themselves — in spite of the fact that the majority of mentally retarded persons **are** capable of setting life goals and communicating their desires and needs. Even the non-verbal, profoundly retarded can often select among alternatives, such as foods, if given the chance.

Although most contemporary residential programs officially advocate the development of independence and self-actualization, few chances are really provided to practice this objective. In most residential institutions, for example, the residents do not participate in any formal decision-making activities with staff.

Unfortunately, the goals of the four interest groups just described do not always coincide. Thus, society's demand for conformity may conflict with the economic advantages of keeping mentally retarded persons within the community . . . Demands that the mentally retarded be economically productive in the institution may lead to dehumanizing practices or conflict with the retarded person's own preferences . . . The parent's desire to humanize their child by developing his social skills may conflict with the little understood needs of persons exhibiting more severe degrees of mental retardation . . . Clearly, clarification of the order of priority among the four groups being served would help the administrator to reach consistent program decisions.

Barriers Between Parents and Staff

The manner in which parents and professionals approach one another frequently makes sound working relationships impossible. Poor communication and mutual distrust are common. Under such conditions, there can be no meaningful relationship between the family and the institution.

In an earlier section, a number of inappropriate ways in which professionals have dealt with parents were described. Thus, professionals have tended to approach relationships with parents as

counseling or therapeutic situations in which inappropriate goals are established (e.g., attempting to help parents "accept" their child's mental retardation, or "lift" their "chronic depression").

It might be more appropriate for professionals to support parents by discussing alternative program plans which would benefit their child.

Professionals also tend to work behind a "veil of secrecy" in their relationship with parents. They withhold so-called "confidential information". Some maintain a god-like manner by independently making decisions which affect a child's future. Others relate to parents as if they were ignorant or out of touch with reality, and automatically discard any information furnished by parents. Endless and wearisome referrals have frequently resulted from professionals' reluctance to either admit their own ignorance or face parents with unpleasant realities.

Parents, of course, have also mishandled professionals. Aggression and unreasonable demands are common. Harassed administrators still see parents as monopolizing their limited time. (Most parents have learned to preface their visit with "I know you're awfully busy, but . . .".) Some parents seek preferential treatment for their own child and grow impatient at genuine delays in implementing programs. In their frustration with inadequate services, parents occasionally attack the dedicated professional who is powerless to remedy the situation.

A state of mutual distrust and suspicion, then, often develops between parents and professionals. Professionals may view the parents as a threat, fearing the possibility of parents monitoring their work and increasing the complexity of their jobs by involving additional persons in program planning, implementation, and evaluation. Parents may likewise view the professional as a threat, sensing that they are being pushed out of the picture and relegated to a helpless position in molding the future of their child.

Toward an Understanding of Problems Associated with Institutional Change

Institutional administrators are faced with no small problem when they attempt to initiate new programs or make program changes. Most institutions in the United States have approximately 1,000 employes. Adequate large scale programming requires the participation of the vast majority of an institution's staff. The major task of the administrator is to determine the direction of programming and gain the cooperation and interest from the staff. The administrator's job is sometimes made very difficult by the subgroups which comprise the institution's staff.

The staff involved in residential programming may be thought of in terms of three primary subgroups: direct care, professional and administrative staff. These three subgroups frequently have negative attitudes toward each other, and differing concepts of "adequate programming".

Resistance from Direct Care Staff

The naive onlooker might assume that new programs simply require training of direct care personnel and designation of the hours when activities are to occur. There are, however, a number of factors which may cause direct care staff to resist the implementation of workable resident programs.

Adherence to established routines. Direct care personnel may vigorously resist proposed changes — even though new procedures might require less physical exertion and speed. The suggestion that residents should be encouraged to develop basic self-help skills is frequently rejected by direct care staff. This change from custodial to developmental programming involves replacing large group "assembly line" approaches with training procedures aimed at achieving individual developmental goals. The latter approach, although ordinarily less boring and strenuous for direct care staff, necessitates a basic change in the status quo. That is, it requires redefining the role of the direct care worker (trainer vs. custodian), and may violate well established beliefs regarding the inability of residents to develop increased self-care and other adaptive behaviors.

When direct care staff do adopt new program approaches, they may attempt to merge the new with the old. Residents may be grouped and staff assigned to small groups, but the practice of doing for the resident what he is capable of doing for himself may continue. In effect, new program approaches and techniques may serve only as surface veneer covering traditional custodial practices. This, of course — since it generally results in little benefit to residents — appears to justify the direct care staff's belief that the established way is the best way. Even if programming does not suffer predicted failure, direct care staff can find some security in the belief that the present administration will be short lived, and that it will soon be possible to get back to the old ways again (average tenure for superintendents in the United States is two to three years).

Inter-shift conflicts. New programs and program changes can also be undermined by the conflict which traditionally exists between shifts. There is often an ongoing feud between the three shifts which destroys adequate communication and cooperation. Effective programming requires that all shifts work closely and cooperatively. Moreover, programs cannot be effective unless all staff working with the resident are striving toward the same goals with the same techniques. When shifts do not communicate or when they become overly jealous or defensive, they cannot effectively implement goal-oriented programs. Major clashes between shifts have been known to occur as a result of rather trivial problems (e.g., one shift claiming primary credit for advances made by a given resident).

Many innovative and creative personnel leave the institution because nearly any change in the status quo appears to result in

shift conflict. In some cases, shift conflict seems to serve the purpose of removing co-workers who are dissatisfied with established practices. This supposition appears more tenable when one considers that the majority of turnover occurs repeatedly in a small number of positions, while there is a relatively stable large "hard core" group of direct care staff.

Loss of motivation through delays. There is also a tendency for new programs or program changes to be rejected by direct care staff because of frequent lengthy delays between the start of the program and the arrival of all needed materials and equipment. These delays are often caused by the facility's elaborate, time-consuming purchasing procedures. Many states require a bidding process for almost all items purchased; this involves a review of bids, an order from the lowest bidder, and a very liberal delivery period, often exceeding three months. Even after delivery, many items are further delayed by lengthy receiving and processing procedures within the institution itself. Months may be lost between the time of ordering items typically used in dorm programs such as tables, chairs, mirrors, arts and crafts materials, recreational and motor development equipment, etc., and actual delivery of such items to the living unit.

Lack of supervisory effectiveness. Much of the resistance shown by direct care personnel should be eliminated or minimized by immediate supervisory staff. The effectiveness of supervisors is, however, sometimes limited by their tendency to identify strongly with direct care staff. Most supervisors work their way up through the institutional ranks, and continue to feel an inhibiting closeness to "co-workers". Supervisors also usually remain in the same area or within the same group from which they were promoted, thus encouraging "inbreeding" of attitudes and program philosophies. Many supervisors seek approval and acceptance from the direct care staff to the extent that they are powerless to supervise and direct the work activities or intervene in conflicts between individuals or shifts.

Some supervisors may also have an inhibiting effect on programming because of the security and safety which they have found in the status quo. Most supervisors assume their position because they survive within the system long enough to be promoted. Since the supervisor is a key figure in program implementation and continuation, it is unfortunate that the qualifications for a supervisory position often stress tenure over achievement and performance.

The other side of the coin. Much of the apparent inflexibility, uncooperativeness, and hostility on the part of the direct care staff is the product of a long history of mishandling by professional and administrative staff. Direct care personnel have usually not been afforded the consideration which they deserve by virtue of the importance of their job. They are constantly reminded that they occupy the lowest rung in the institutional job ladder by the way

in which they are treated and by the shamefully small salaries which they are usually paid. Direct care personnel are continually subjected to demands from other departments (e.g., food service, maintenance, social service, psychology, medical, recreation, nursing, etc.). Many of these demands are inconsistent or incompatible. For example, supervisors may demand that more time be spent cleaning the living unit; psychologists demand more time for training; physicians demand that more staff accompany residents to morning clinics, special referrals, and emergency treatments; and recreation workers demand assistance in indoor and outdoor activities. Direct care staff thus frequently find themselves in the untenable position of being expected to simultaneously recognize and respond to the incompatible demands of a variety of staff members.

Resistance from Professional Staff

Adherence to traditional roles. Many professionals working in residential facilities feel that their time and energies are best spent in performing certain specific functions for which they have been trained in colleges and universities. Thus, the role of the psychologist in a residential setting has traditionally been defined in terms of administering and interpreting intelligence and personality tests, conducting psycho therapy and counseling sessions and, where feasible, implementing basic research studies in the behavioral area. Similar role expectations have been developed for social workers, physicians, nurses, etc.

Many of these traditional functions, however, have little direct impact upon the daily lives of the mentally retarded residents. Thus in many large institutions, it is not uncommon to find masters and doctoral level psychologists spending the vast majority of their time conducting routine psychometric evaluations and writing reports which go into the departmental files to remain unread — until another psychologist decides to evaluate the same resident several years later. The cost of such basically futile efforts is often staggering. In reality, many of these traditional functions can be performed by less trained workers under appropriate professional supervision (e.g., case aids can be readily trained to conduct intake interviews and prepare case histories; psychometrists can be employed to assume routine testing duties).

The implementation of sound developmental programs requires the pooled expertise of all professional disciplines. This means professionals must go well beyond their traditional roles by serving as members of multidisciplinary teams responsible for: (1) designing detailed program plans for specific groups of residents; (2) training and assisting direct care personnel in program implementation; and, (3) evaluating the program's effectiveness in meeting the goals established for individual residents. The concept of team programming is discussed in more detail in a later section.

Due to their training and orientation, many professionals are extremely resistant to assuming duties which go beyond their

traditional roles, including active participation in multidisciplinary program development teams. The responsibility for designing resident training programs thus often remains ill defined.

The ivory tower approach. Because of the restricted roles which they have assumed, professionals in residential facilities are frequently accused of taking an idealistic or "ivory tower" approach to resident programming. Thus, direct care staff often view professionals as idealists who are basically ignorant of the day-to-day activities and problems on living units. The program suggestions which may be made by professionals are, therefore, often seen as unrealistic and potentially damaging in terms of maintaining a smoothly functioning institution. When such attitudes are held by direct care staff, a general unwillingness to implement new program concepts results.

Indeed, the "ivory tower" image of the professional is often well deserved. Many professionals rarely, if ever, have contact with residents on the institution's living units, spending the bulk of their time in comfortable, well furnished offices. The fact that many living units are poorly heated and lack air conditioning may well be a contributing factor to this unfortunate situation.

Professional aloofness. Many professionals encourage criticism and hostility by relating to residents and direct care staff in a manner which accentuates status differences (e.g., expecting attendants to interrupt their activities whenever a professional visits a living unit, but requiring attendants to make appointments to discuss resident problems with professional staff). When interacting with direct care personnel, the professional often assumes a condescending and patronizing attitude.

In relating to residents on the living unit, many professionals vigorously avoid any type of physical contact. Should the resident attempt to shake hands or otherwise initiate bodily contact (e.g., hugging) some professionals have been known to dash to the nearest sink to immediately scrub their hands. When observed by direct care personnel, such behavior is not likely to enhance the image of the professional.

The delusion of professional omnipotence. As indicated in an earlier section, professionals sometimes treat parents as if they had little or no knowledge of their child's problems, needs, and feelings. Such behavior is not limited to families of the retarded. Although direct care staff are probably the institution's richest source of information regarding residents, their advice is seldom sought or given serious consideration in the formulation of program plans. In fact, professionals often allude to the ignorance and incompetence of direct care personnel, using them as scapegoats when attempting to place blame for the failure of ill conceived and poorly planned program efforts.

The professional also faces problems. Much of the professional's concern for status and accompanying lack of concern for resident

needs is the result of a long history of mishandling. Professionals often have to develop and design programs for residents under severe restrictions. Proposed programs ordinarily must meet the requirements for safety imposed by the superintendent, sanitation and health criteria imposed by the medical director, and economic restrictions dictated by the business manager. After programs have been reviewed and modified by each of these key administrators, the end result is often a drastically watered-down version of the original proposal, which differs in few respects from the status quo. After several such encounters, the professional may decide it is safer and less frustrating to support the existing system.

Even more aggressive and dedicated professionals may eventually succumb to the established system because of the slow pace at which change occurs, despite constant pressure. In one of the newer institutions, for example, it was proposed that young semi-ambulatory residents be grouped on the living unit and removed from wheelchairs for a major portion of the day. Because of a lack of space and the custodial design of the living unit, partitions were requested to convert large sleeping rooms into training and activity areas. After six months of writing requisitions, justifications, and defending the program to the administration, the proposal was accepted. The medical department voiced concern over children being placed on floors and the possible communication of disease; the business manager voiced concern over the possible damage to the physical plant resulting from renovations; and the superintendent was concerned about parent reaction and the possibility of injuries. An additional twelve months passed before the institution's maintenance department completed physical renovations, and needed equipment such as floor mats, small tables and chairs were borrowed from other areas of the institution. Eighteen months elapsed between the proposal of the program and its implementation.

Resistance at the Administrative Level: Illegitimate Goals

Most administrators are deeply committed to the goal of providing the best possible programs for the residents of their facility. There are, however, other "illegitimate" goals sometimes implicit in the service system which tend to preempt the needs of the mentally retarded.

Systems maintenance. One of the more common illegitimate administrative goals involves an attempt to protect and perpetuate the current system within which the administrator is operating. In serving this interest, administrative decisions are largely determined by the need to protect existing practices, procedures, and traditions. Often, continuation of the existing situation is justified on the basis of past fiscal investments. Thus, in comparing cost of several program alternatives, the past cost of the existing program is included as a "saving" in comparison to future costs of alternative approaches. It is sometimes argued that abandoning unsuitable insti-

tutional buildings, for example, cannot be justified economically because of past costs incurred in construction, maintenance, and refurbishing.

Self-preservation. In general, innovation increases the vulnerability of an institutional staff. Frequently, an administrator's status is threatened primarily by "sins of commission" rather than by "sins of ommission". A "play safe" strategy — aimed at minimizing risks — becomes an unwritten institutional policy. Once established, bureaucracies are extremely resistant to change. Self-protective policies and the vested interests of the staff overshadow program goals.

Maintaining the balance. Typically, institutions are potentially explosive social systems in which intrigue and power struggles among departments are commonplace. The successful administrator is able to maintain a continuous homeostasis within the institutional system, but any change endangers the balance of power. Administrative decisions may often be the result, therefore, of attempts to minimize internal conflict. Adoption of a "don't make waves" strategy is a favorite administrative recourse to ensure "peace and quiet". It is not unusual to find that special demonstration projects are isolated from the institution itself, both geographically and operationally, to minimize the potential disruptive impact.

Self-aggrandizement. Some administrators may be strongly motivated by a need to build personal empires. Such administrators tend to enlarge their management staffs beyond all reason. This "management pyramiding" is usually accompanied by massive distribution of policies, manuals, procedures, and other "guardians of the empire". This need for self-aggrandizement or personal status may also occur within the departmental structure of the institution. The keen competition between departments and the need for autonomy and power frequently result in departments acquiring a staff which far exceeds actual needs. Whether empire building occurs at the top administrative or departmental level, the result is an institutional setting which is staff rather than resident oriented.

Management monopolies. Some administrators who happen to be members of particular professions adopt a technocratic administrative style aimed at establishing management monopolies which serve to increase **their** profession's power and status. The justification for this attitude is that only "certain" professions can administer programs for the mentally retarded. The rationale developed to support this position is usually a form of the following "syllogism to power": 1) mental retardation is a (medical, psychological, educational, etc.) problem; 2) only (physicians, psychologists, educators, etc.) can direct (medical, psychological, educational, etc.) problems; 3) therefore, only (physicians, psychologists, educators, etc.) can administer mental retardation programs. This type of pseudo-logic is a particularly destructive one, regardless

of the profession making the bid for power .The strategy has been so successful in some states that state laws decree the specific profession of their institutional administrators!

Resistance at the Administrative Level: Misplaced Concerns

Some administrators may resist the adoption of programs based on developmental principles because they sincerely believe that existing program approaches are appropriate for the residents. Since existing program approaches often reflect the administrator's basic attitudes toward the mentally retarded, it may be quite difficult to gain acceptance of new attitudes and program strategies. Administrators who defend inadequate or inappropriate programs frequently disclose a misplaced or over-concern for safety, health, economy, and/or happiness.

Over-concern for safety. Some administrators believe that the mentally retarded require an unusually safe environment. Over-concern for safety often results in exaggerated tendencies to protect residents from the environment, other persons, and even themselves. Unreasonable concern for protecting residents is often reflected in practices such as:

- **Restricting the mobility of young residents;**
- **Excessive use of restraints to protect other residents or to protect residents from themselves;**
- **Limited availability of toys;**
- **Lack of interior decorations such as lamps, mirrors, and pictures;**
- **Locked dormitories;**
- **Restricting physically handicapped residents from living with non-handicapped residents;**
- **Restricting physically handicapped residents and residents with convulsive disorders from school attendance; and,**
- **Restricting residents from using tools such as hammers, saws, and drills and appliances such as stoves, irons, and sewing machines.**

Of course, certain levels of safety must be provided — but safety should not be stressed to the extent that protection overshadows learning, growth, and development. Administrators who stress safety to a debilitating degree generally perceive the institution as the "home" of the residents, with the staff as "parents", and residents as "eternal children" who will always be dependent and need supervision. An overly paternalistic environment shelters residents from the necessary levels of risks which are an integral part of developing self-help and independent functioning.

Overconcern for health and sanitation. Some administrators exhibit an overconcern for health and sanitation which results in the establishment of a hospital-like environment and an emphasis on the physical aspects of the resident. Practices which indicate an overconcern for health and sanitation include:

- Referring to residents as "patients";
- Programs are referred to as "treatment" or "therapy";
- Restricting residents from playing on the floor;
- Spending an inordinate amount of time cleaning building interiors;
- Emphasis on records, charts, and graphs;
- Requiring residents to have close-cropped hair;
- Nurses supervising living units in which well residents reside,
- Proliferation of medical personnel and services instead of educational personnel and services; and,
- Living units referred to as "wards".

Maintenance of health should be considered a part of education and training rather than a major area of program focus. Emphasis on the physical aspects of residents may result in a de-emphasis on other important developmental areas such as self-help, social skills, communication, and even educational and vocational skills.

An emphasis on health and sanitation is often accompanied by the premise that the mentally retarded are sick or diseased. This generally results in the development of treatment regimes and a physical setting appropriate for sick people. The application of this approach to the mentally retarded is totally inappropriate. In the traditional sense, "treatment" is directed toward "cure" or a return to normal functioning. Since the mentally retarded are not sick, "treatments" fail to bring about a "cure", and the result is frequently an atmosphere of defeat and hopelessness and reinforcement of the belief that the mentally retarded are indeed beyond help.

Overconcern for economy. Some administrators exhibit an overconcern for economy which results in minimal services in an unstimulating setting. An overconcern for economy may be reflected in:

- Massive overcrowding of buildings;
- Inadequate number of professional and direct care staff;
- Buildings which are underfurnished with simple, indestructible fixtures (e.g., metal benches);

- **Inadequate supply of training equipment and materials;**
- **Excessive use of resident workers to supplement staff.**

An unreasonably stressed economy of services strongly indicates that mentally retarded persons are viewed as sub-human organisms. There is, moreover, the implied belief that training and education to foster socially accepted skills and behaviors such as independent toileting, eating, dressing, etc., is inappropriate — since residents are not considered to be capable of human qualities and characteristcis. Such a concept is frequently reinforced by the type of approach used. Since residents are not trained and educated, they do not develop — therefore, they appear incapable of development.

Overconcern for "happiness". Administrators should, of course, be concerned with the happiness of residents. However, overconcern for residents' happiness is sometimes used to justify the abandonment of developmental goals. Overconcern for happiness may be reflected in the following ways:

- **Residents are not "pushed" to achieve a level of development commensurate with their potential;**
- **Residents are allowed to eat excessively without proper regard for obesity;**
- **Capable residents are retained in the "safe" and "happy" environment of the institution. They are not encouraged to assume responsibility for their own affairs in the community; and,**
- **Residents are encouraged to engage in activities which are inappropriate to their chronological ages and social capabilities; (e.g., adult women playing with dolls or adult men dressing as cowboys).**

Developmental goals must take priority over hedonistic considerations. Progress can be painful, but it can also lead to happiness on a long-range basis. Mentally retarded persons should not be denied the joy of achievement. This principle applies to non-retarded persons, and mentally retarded persons should have the same right to develop.

EXTRA-INSTITUTIONAL PROBLEMS

The larger bureaucratic system within which the institution operates is often as rigid and formal as the institution itself.

Bureaucratic sluggishness. When policy forces institutions to obtain a central office clearance for program changes, considerable delay can be expected. Very likely, a long series of requests, modifications and replies will ensue before actual program implementation. In many cases, the rate at which the system responds to proposed change lags far behind resident needs. Proposed programs are frequently subjected to review and approval by a number of state agencies which may not even be a part of the agency which operates residential facilities for the mentally retarded (e.g., long-range planning and budget agencies). If communication between state agencies is poor, there may be long delays in developing and implementing new residential programs.

Central office control. An additional problem related to the bureaucratic structure is the degree of influence and power central regulating agencies have in the operation of institutions. In the past, central offices have exerted little or no power or authority over institutions (e.g., in some states superintendents of large facilities have operated with almost total autonomy). The recent trend, however, has been to enlarge the staff of central offices and increasingly exert more authority over institutions. As central office staffs increase in size, they have assumed increasing responsibility for program design and implementation. Much time and energy have been required of institutional staff to gather information, prepare reports, and respond to specific demands which may or may not directly relate to the operation of the institution. These may include demands for "political favors" such as early admission of specific applicants and mandates to hire certain employees.

Inappropriate use of power. The relationship beween the central office and an institution is at times not clearly defined. This is due to a tendency for central office staff directors to operate as if they had line authority over institutional staff who represent their particular discipline (e.g., medicine, psychology, social service, business, food service, engineering, etc.). There has been a tendency for central office directives to be sent to a particular discipline or supportive service in the institution. This confusion of "staff" and "line" functions has at times excluded the institution administrator in critical decision making.

Fiscal restrictions. Fiscal control may serve to impede program innovation. In many states, administrators are overly restricted in designating the use of budgeted funds. They may be required to submit detailed justification to one or more state agencies for any proposed budget modification. When administrators are thus restricted, practically all decision making is the prerogative of the state budget agency. In some states, however, institutions are allo-

cated lump sum budgets which permit flexibility in the use of funds, thus encouraging program innovation.

Civil service and unions. The existence of civil service or merit systems can also impede institutional change. These systems often include rather rigid job descriptions which are very difficult to change. If, for example, a "hospital aids" job description reflects building maintenance, physical care of residents, and record keeping as primary job responsibilities, a person having such a job description may not be used in educational programs until a new job description is developed and adopted. The unionization of direct care staff has also impeded program innovation and progress in some states. Unions have been known to adopt overly protective postures with regard to their members (e.g., vigorously fighting the termination of employees who have abused residents in front of witnesses). Strikes which threaten the welfare and safety of an institution's residents have also been threatened. Direct care staff should not be denied the right to unionize; however, the needs of the residents must not be obscured in union-administration power struggles.

Strategies for Implementing Change

The most common strategies which institutions have used to modify programs and to implement changes in operational philosophy have been inservice training, redeployment of staff, the establishment of demonstration projects, research programs, and college or university affiliations. Parents should, therefore, be particularly concerned with these approaches when they seek institutional change.

Inservice training programs. The initiation of new programs requires upgrading of staff and a change in the operational philosophy which may have justified a lack of programs or sustained inadequate programs in the past. Inservice programs have been used as a major vehicle for introducing new programs and promoting new program philosophies. Most institutions which have utilized inservice programs have focused on the direct care personnel at the living unit level.

Many inservice training programs have been inadequate in several major respects. First, many have failed to adequately involve supervisory personnel, who exert the greatest control over staff behavior at the living unit level. Failure to include these very influential staff members has frequently resulted in a perpetuation of old programs and old program philosophy in spite of inservice training efforts. Secondly, inservice programs have tended to be modeled after the classroom approach wherein direct care staff are removed from the living units for training sessions. The result has generally been minimum carry-over from classroom lectures to actual problems at the living unit level.

Thirdly, and perhaps most important, the content of many inservice training programs has not been geared toward resident training needs. Traditionally, inservice programs have focused upon three basic areas: (1) an overview of mental retardation, including definitions, levels and commonly-found syndromes; (2) physical care techniques for attendant personnel to use in meeting resident needs; and (3) a detailed review of institutional policies, practices and traditions. Such a curriculum has tended to reinforce custodial role expectations for direct care staff. Insufficient emphasis has been placed upon the role of the attendant as a trainer, including specific techniques which may be used in initiating sound resident training techniques.

All personnel involved in the education and training of residents should be active participants involved in inservice programs. Inservice training teaching methods should ensure carry-over from the inservice setting to the living unit. Some institutions, in an effort to involve more personnel and to ensure learning relevant to the living unit setting, have utilized teaching methods including role playing, management seminars, sensitivity training, programmed instruction, audio-visual aids, closed circuit television, and video taping.

Redeployment of Staff

Because of the marked staff inadequacies which plague most residential facilities, administrators are becoming increasingly aware of the need to obtain maximum efficiency and productivity from existing personnel. Traditionally, institutional staff have been organized according to a departmental model. In recent years, however, there has been a movement toward redeploying staff according to administrative models aimed at better serving resident programming needs.

The departmental approach. Service delivery approaches have been customarily based upon a departmental, or discipline-oriented model. Thus, departments of cottage life, psychology and medicine have been established and charged with the responsibility for meeting the needs of the facility's entire resident population. Members of each professional department are generally housed together, often in a large administration building. As a result, professional staff are relatively isolated from both residents and direct care personnel. In addition, communication between departments is restricted, with each tending to develop its own programs without sufficient regard for the needs, goals and activities of other disciplines. This approach has often resulted in an unhealthy competitiveness between departments, characterized by non-productive conflicts, power struggles and attempts at empire-building. The group that suffers most from this unhealthy situation is, of course, the facility's mentally retarded residents. Their needs may well be lost in the struggle to gain status in the institutional hierarchy.

Under the departmental approach, responsibility for developing programs for specific groups of residents is ordinarily poorly defined. Considerable latitude is available for "buck-passing", and an inordinate amount of professional staff time may be devoted to the "more promising" or "more attractive" residents. This approach is largely an offshoot of the old medical model, in which there were distinct lines among disciplines and between professional and non-professional staff.

The combined departmental-unit approach. Some residential facilities have attempted to make more effective use of professional staff by combining a unit approach with the traditional departmental structure. Under this model, residents are divided into sub-groups, or units. A multidisciplinary team (e.g., psychologist, social worker, physician, cottage life supervisor, recreation worker, etc.) is given the responsibility for designing and implementing a comprehensive array of programs for each unit. Members of the multidisciplinary team are often housed together in close proximity to the residents for whom they are responsible (e.g., in a group of offices on one of the living units). This approach to programming offers the potential for providing comprehensive programs designed to meet resident needs. Specific responsibilities are more easily assigned than under the traditional departmental approach, and the effectiveness of each team member may be more readily evaluated.

This approach is administratively complex, since the unit structure is superimposed upon the traditional departmental organization chart. Lines of authority are thus sometimes difficult to define. A member of each team is ordinarily appointed as Team Coordinator. In some cases, the functions of this individual are limited to coordinating the activities of his fellow team members (i.e., the Coordinator may have no line authority over the other professionals with whom he works). In other facilities, a member of each team is appointed as Team Director, and given supervisory authority over other members. This strategy can result in an administrative dilemma, since other team members are responsible to two "bosses" (i.e., their department head and the Team Director).

The unit approach. In some institutions, the department organization structure has been totally abolished in favor of a unit approach. This model is basically the same as the combined department-unit approach (i.e., multidisciplinary teams are assigned program responsibilities for specific groups of residents). However, by doing away with traditional departments, the problem of dual-reporting relationships and allegiances is eliminated.

Assignment of unit teams: levels vs. program needs. Under either the combined department-unit or the unit approaches, it is necessary to determine the basis on which unit teams will be assigned to resident sub-groups. One approach is to assign multidisciplinary teams to residents grouped on the basis of levels of mental retardation and special handicaps (e.g., a team for each of the four levels

of mental retardation, a fifth for the semi-ambulatory, and a sixth team assigned to non-ambulatory residents). An alternate strategy is to assign teams to resident groupings based upon program needs (e.g., teams for development and training, education, vocational rehabilitation, etc.). Under this approach, young mildly retarded residents might be viewed as having basically the same program needs as older severely retarded residents, and would thus, for a period of time, be assigned to the same multidisciplinary team.

Although redeployment of staff according to a departmental-unit or a unit approach can greatly facilitate staff-resident interaction, it is apparent that professional staff cannot be expected to actually implement resident training programs through a one-to-one relationship. Rather, the responsibility for direct implementation of training programs is assigned to direct care personnel. Professionals should, however, be expected to function as consultants, teachers, trainers and supervisors to those who provide direct services at the living unit level.

An additional advantage of the team approach is that it enables the residential facility to make better use of volunteers and student trainees. Under a team model, it is possible for members of these groups to become directly involved in resident programming activities, rather than being limited to less stimulating traditional functions.

A relatively new model of service delivery has resulted from the need for continuity of the various therapeutic and educational programs conducted within the facility. The manner in which teams function to assure this continuity of programs has been labeled the **Cross Modality** approach. In this approach, professionals retain their traditional responsibilities but relinquish duties and tasks which can be safely assumed by others. In essence, there is a partial role exchange wherein each professional discipline that is represented in the team shares skills and knowledge with other team members including direct-care personnel. Implementation of the cross modality approach usually requires special training and willingness on the part of professionals to relinquish many of the duties they have exclusively performed in the past. Where the cross modality approach has been used experimentally, the team members have been quite enthusiastic about its merits as a viable strategy for program implementation.

Demonstration Projects

Most institutions still operate under severely inadequate budgets and cannot afford to implement large-scale training and education programs on a trial basis. Many institutions attempt to overcome their financial handicaps by utilizing demonstration projects to test the adequacy, effectiveness, and value of special program approaches and techniques. These small scale programs are valuable for demonstrating program effectiveness to the larger institutional

staff and in justifying requests for increased budgets which will allow expansion of such projects. However, as indicated previously, demonstration projects may be geographically and operationally isolated from the remainder of the institution in order to minimize their potential "disruptive" influence on traditionally oriented staff. Such projects may also serve as a veneer to cover general program inadequacies. That is, parents, politicians and other visitors may be taken on tours of units having demonstration projects, but not be permitted to visit more typical living units where little or no meaningful programming is taking place.

Research programs. Research programs should be an integral part of services to residents. Research can be an effective tool for evaluating and refining educational or training techniques. It also serves to foster recruitment and retention of professional staff.

Due to limited professional staff resources, most research in residential facilities is conducted by outside personnel (e.g., faculty from a nearby university). Such studies are usually aimed at answering questions which may be of great interest to the outside investigator but of little relevance to the daily living needs of the mentally retarded residents. In those institutions which do employ a full time research staff, studies are often equally esoteric. There is a need, therefore, for residential facilities to place increased emphasis upon operational-programmatic research aimed at meeting **resident** needs (e.g., a comparison of the relative effectiveness of alternative approaches to teaching self-care skills).

Educational affiliations. College and university affiliations can be valuable to the institution. Joint relationships between institutions and educational settings stimulate an exchange of information which may provide a basis for innovative program approaches and techniques. In addition, joint participation between institutional staff and students can be a potential resource for recruiting manpower for the field of mental retardation. These affiliations are strongly encouraged by a number of available federal grants. Hopefully, administrators and professional staff will view such affiliations as a two-way educational process. That is, rather than attempting to indoctrinate the student in traditional approaches to mental retardation, professional staff should capitalize upon this opportunity to acquaint themselves with new and innovative approaches to programming being taught at the college or university.

HOW HAVE PARENTS BEEN INVOLVED?

There is general agreement that parents should be involved in programming for their child. but there is considerable disagreement as to the extent of this involvement.

Sharing information with parents. Most residential administrators would, for example, agree that parents should be kept informed of their child's progress, but some still feel that certain information should be withheld (e.g., intelligence tests scores, caseworker reports, diagnoses, prognoses, medications, treatment plans, etc.). The rationales for withholding this type of data is that parents would not understand technical information, would misinterpret and misuse it, or that such information might lead to a greater maladjustment on the parent's part. Generally, however, the unstated reasons are that institutional staff are unskilled in "translating" their information into terms meaningful to persons outside their profession or specialty area. It is also feared that parents might detect problems and demand changes which would disrupt the equilibrium of the institution and threaten the security of the institutional staff.

Involving Parents in the Decision Making Process

There is a divergency of opinion among administrators concerning the extent to which parents should participate in decisions which affect their child. Some institutional administrators see their roles as a "grave responsibility", and feel that to ensure the safety, security, and health of the resident no one other than the administrator should make decisions. Other administrators allow parents to make decisions peripheral to programming (e.g., the scheduling of visits home, or the type of clothing sent to their children). Frequently, there are even restrictions placed on these areas. Parents are rarely allowed to participate in decision making in program areas such as dormitory placement, training and education options, selection of optional medical procedures, etc. Their involvement is generally limited to signing "release" forms to approve a course of action that has already been decided upon by the administrator.

Parents of noninstitutionalized persons typically participate in such matters — so institutionalization is not a valid basis for denying parents the right to take part in all major areas of decision making — not if the concept of normalization and the importance of the family unit is sincerely subscribed to by institutions.

Parent groups. The relationship of parent groups to institutions has been traditionally vague. Some parent groups have become only superficially involved by giving parties, decorating dorms, making special equipment in workshops, or promoting fund raising. Other groups participate in the management and program planning of living units—still others take part in the institution's plans, programs, and budgets on an immediate and long-range basis.

Parents as volunteers. Most institutions encourage parents to serve as volunteers, but frequently prohibit them from activities which would bring them into direct contact with their children. A number of elaborate reasons have been developed to defend this practice — all are invalid when they serve as blanket policies which tend to further erode the family unit.

Parent volunteers are generally restricted to performing peripheral activities such as letter writing, taking residents for walks, sewing, mending, etc. Some parent volunteers, however, serve the institution in a valuable and constructive manner. After specialized training, they are assigned to professional teams to assist in areas such as psychological testing, speech therapy, and the implementation of conditioning programs.

Parent anxieties. In some cases, both individual parents and parent groups lose their effectiveness by becoming too passive and fearful to confront administrators. In effect, they develop a "hostage syndrome"—the fear that any challenge of the institution's operation will result in a decline in services to their children.

HOW SHOULD PARENTS BECOME INVOLVED

No single strategy will cover all parental efforts to effect change in residential facilities. NARC's **Handbook for State and Local Residential Services Committees** outlines a number of possible suggestions. The following are several highlights from that publication:

- Take the lead in decreasing distrust and suspicion on the part of institutional administrators and their staff . . .
- Learn the problems administrators face — let them know you recognize these problems . . .
- Become familiar with the broad range of possible programs, and particularly those which have worked successfully in other institutions . . .
- Let administrators know you are aware of residents' needs, and the existence of programs in other institutions which meet these needs . . .
- Make every effort to form a team relationship with each administrator. Offer your assistance in areas in which he might be limited because of his position (e.g., influencing public officials, publicly criticizing unfavorable legislation, and lobbying for adequate budget requests) . . .
- Participate — or be represented — in program planning, implementation, and evaluation; policy making for the institution, establishment of institutional procedures, and the development of institutional goals . . .
- Make sure that you, as parents, are represented at regularly scheduled and special staff meetings and conferences so you are aware of problems and progress in the day-to-day operation of the institution . . .
- Once you have established a working relationship with institutional administrators and staff, make sure future parent representatives will be able to continue that relationship. Record the activities and accomplishments of the relationship and establish a method of communicating goals, policies and procedures of the parent force (i.e., written materials and training sessions) . . .
- Parents should agree on critical issues before meeting with the administrator or staff. Disagreement among parents at the time of a meeting can reduce their credibility and increase resistance to parent involvement . . .
- Parents can further help administrators by obtaining services which complement the developmental goals of the institution. Institutions should have access to community-based day care facilities, special education classes, sheltered workshops ***and*** community residential facilities. Parents can assist institutions by informing the community of the needs

of the mentally retarded and influencing local officials. In some cases, administrators may resist efforts to develop community-based programs, particularly residential facilities, fearing that this will weaken the position of their institution. Parents should seek to overcome this resistance in a constructive fashion. They ***should not***, however, allow themselves to be diverted from the critical task of vigorously fostering the development of sound community-based services, including residential programs . . .

- Help obtain needed services and equipment for the institution. Promote special fund drives for projects and equipment, or encourage the donation of items such as television sets and playground equipment which are not provided for institutions by some states . . .

- Encourage public support of or resistance to legislation, as the situation warrants; carefully assess each legislative effort. Is it potentially beneficial or detrimental to the needs of the mentally retarded? Efforts must, of course, be coordinated with the state governmental affairs committee . . .

- Meet with residential facilities' budget committees to review budget requests. A better understanding of their needs puts you in a better position to work for or against adoption, and — access to budget proposals is essential in order to make informed decisions. Budget requests should be reviewed with an eye for appropriate programming. Don't assume that "more" money will automatically result in better services . . .

- Knowledgeable residential service committee members should arrange to meet with legislative committees, councils, or commissions to answer questions or present testimony on matters pertaining to residential programming. Such arrangements should be made in cooperation with your governmental affairs committee . . .

- Reports, projects, ideas and materials developed or received by parents should be shared with the ARC governmental affairs committee. This committee's task is to educate or persuade key legislators who serve on committees which consider residential services legislation. Pertinent back-up data is most important to further their efforts . . .

- Timely newspaper TV and radio coverage of the state ARC's stand on legislative efforts can be most effective in getting legislation acted upon. In order to present a united front to the public, be sure such coverage is planned with staff or state publicity committees . . .

- ARC's should establish liaisons with other organizations having shared concerns for the right and welfare of the developmentally disabled (e.g., the United Cerebral Palsy Association, the Epilepsy Foundation of America, the Council for Exceptional Children, etc.) . . .

- If parents are to be effective in implementing change, they must be aware of the authority relationships which exist between the residential facility and the state agency responsible for mental retardation services. The formal power structure may be determined from organization charts depicting lines of authority. In many cases, however, the informal power structure will bear little resemblance to stated organizational relationships. Thus, though formally responsible to the state mental retardation agency, superintendents with tenure may operate in a totally autonomous fashion. Although such information is usually difficult to obtain, parents should attempt to determine where the true focus of power lies.

PARENTS IN THE ACCREDITATION PROCESS

The Accreditation Council for Facilities for the Mentally Retarded (ACFMR)

The Accreditation Council was established to improve, through a national, voluntary program of accreditation, the quality of services provided mentally retarded persons.

In 1952, the American Association on Mental Deficiency (AAMD) published a special committee report on standards for institutions. Seven years later the AAMD's Project on Technical Planning in Mental Retardation undertook a major standards development project culminating in the 1964 **Standards for State Residential Institutions for the Mentally Retarded.** During this period, NARC and the American Psychiatric Association (APA) also evidenced interest in the development of standards. These organizations were concerned with building upon the AAMD experience toward the establishment of a formal accreditation program. Recognizing the need for interagency cooperation in such an endeavor, the AAMD formed in 1966 the National Planning Committee on Accreditation of Residential Centers for the Retarded, composed of representatives of AAMD, APA, Council for Exceptional Children, United Cerebral Palsy, and NARC. These five organizations—plus the American Medical Association which is a member organization of the Joint Commission on Accreditation of Hospitals—comprise the current Accreditation Council for Facilities for the Mentally Retarded.

As indicated in an earlier section, although the Council is charged with the adoption of accreditation standards, drafting of the standards was accomplished through the contributions of 200 individuals including representatives of 42 national organizations. Twenty-two committees wrote the standards and their work was reviewed and critiqued by three additional committees representing administrators of public and private facilities and state programs for the retarded, and consumers of residential services.

The resulting standards document was adopted by the Accreditation Council in May, 1971. The voluntary accreditation of residential facilities began in early 1972.

The Accreditation Council's standards differ from those previously developed by AAMD in three important respects:

(1) **Goals:** The AAMD standards were designed to be generally attainable by most institutions within a five to ten year period. While this was a laudable goal, ideas of what "may" be obtainable are likely to be limited by existing service models. The ACFMR standards, on the other hand, are geared toward services which are "necessary or desirable for providing a fully adequate program".

(2) **Focus:** The AAMD standards placed strong emphasis upon the demographic characteristics of the institution (e.g., staff to resident ratios, numbers of professional staff in each de-

partment, etc.). While important, these statistics do not indicate how effectively available staff are used to meet resident programming needs. The ACFMR standards, however, **do** focus upon programs for individual residents.

(3) **Evaluation Mechanisms.** The AAMD accreditation process depended upon peer review. That is, an institution would be evaluated by a team of superintendents of institutions in other states. Under the ACFMR program, evaluations are conducted by trained evaluators employed by the Council.

The ACFMR standards and evaluation procedures represent the greatest single breakthrough in residential services in the past several decades. It is critical, then, that parents work diligently to ensure their application on a nationwide basis.

The role of parents. The accreditation process can provide a most effective avenue for parental involvement in residential services. Parents should actively seek commitments from governors, commissioners, and deputy commissioners of mental retardation to have their state's residential facilities participate.

The first phase of accreditation requires a residential facility to perform a self-study to objectively determine its own status. This study also furnishes information to the accrediting body for determining the feasibility of an on-site evaluation. Parents can be an asset to the institution during this self-study period by assisting the institution in judging the effectiveness of its programs. Parental input should, in fact, be considered as a major source of information in the self-study phase.

Parents should involve themselves in all phases of the accreditation process. Only through such involvement can they become knowledgeable of an institution's strengths and weaknesses. And—regardless of an institution's ability to attain accreditation, all information gained through the process can be used to work with administrators toward needed improvements. Once accreditation is attained it can be used as an effective tool to influence governing bodies or agencies which fund or set policies for residential facilities. Parents should assist administrators in making certain accreditation is fully utilized in making needed changes such as more adequate budgets, sufficient personnel, and necessary modification of inappropriate physical plants.

State governmental affairs committees should also become involved in accreditation—from the very first stages of the process. With their specific knowledge of institutions' needs, they can be of great assistance in dealing with legislators and other state officials.

Parents should make every attempt to work constructively with administrators. If, however, all cooperative efforts fail, they should then approach the central offices which control the institution. If institutional changes cannot be attained at this level, parents should seek representation at the governor's level.

If all such efforts fail, they can then resort to a variety of "backup strategies" (e.g., class action suits and other legal strategies, and massive publicity efforts aimed at increasing public awareness of dehumanizing conditions and obtaining public commitment to change).

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